

VU Research Portal

Spiritual experiences of continuity and discontinuity among parents who lose a child

Ganzevoort, R.R.; Falkenburg, N.

published in

Journal of Empirical Theology : JET
2012

DOI (link to publisher)

[10.1163/15709256-12341249](https://doi.org/10.1163/15709256-12341249)

document version

Early version, also known as pre-print

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Ganzevoort, R. R., & Falkenburg, N. (2012). Spiritual experiences of continuity and discontinuity among parents who lose a child. *Journal of Empirical Theology : JET*, 25(2), 189-204. <https://doi.org/10.1163/15709256-12341249>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

Stories Beyond Life and Death

Spiritual Experiences of Continuity and Discontinuity among Parents Who Lose a Child

R.Ruard Ganzevoort & Nette Falkenburg

Journal of Empirical Theology 25/2 (2012), 189-204

Abstract

This is a study of parents' spiritual experience of the loss of a child. Many parents experience continuing bonds with their deceased child as well as forms of posttraumatic growth. Twelve parents of children dying after severe illness were interviewed about their experiences. The interviews contain stories about premonitions, the intensity of the moment of the child's death and the child's presence after death. Thematically the stories reflect the dialectics of continuity and discontinuity in the relationship with the child. This is interpreted in terms of attributing meaning, significance and comprehensibility.

Introduction

The loss of a child is generally considered to be especially devastating, with parents suffering long and intensely, displaying many symptoms of posttraumatic stress (Dijkstra 2000). Their challenge is to adapt to a new and painful reality in which they have to accept their loss. Inability to accept the death of their child may lead to escalating psychological problems, even to a posttraumatic stress syndrome (Nolen-Hoeksema 1999; Field 2008). Many parents, however, maintain some kind of ongoing bond with, or lasting attachment to, the child. This is not necessarily a sign of maladaptive mourning or refusal to accept the death, but could be a component of adaptive grieving (Rosenblatt 2000; Talbot 2002; Tedeschi 2004). A lasting relationship with the deceased child is not threatening as long as it does not prevent the parent from moving on or acknowledging the reality of the child's death (Field 2008).

The death of a child is associated, not only with trauma, but also with experiences that are valuable to the parents like discovering a new appreciation of life, or rebuilding their own identity. Studies of posttraumatic

growth identify five dimensions: psychological strength, greater empathy, closer relations with others, appreciation of the value and fragility of life, discovering new opportunities, and a new spirituality (Calhoun 2006). These studies broaden the narrow focus on the pathological dangers of bereaved parents to the extended life story of their loss and their grief (Hogan & Schmidt 2002).

Attribution of meaning is essential for coping with the death of a child (Rosenblatt 2000; Talbot 2002). Research by Neimeyer et al. shows that a search for meaning plays a crucial role in the process of readjustment after the death of a loved one (Neimeyer 2006; Keesee, Currier et al. 2008). Fundamental assumptions about living in this world are shattered by traumatic loss (Janoff-Bulman 1992). These include the assumption that the world is benevolent and a sense of one's own worth. The belief that we are somehow protected from the great disasters of life is shattered. It seems essential to find a new sense of coherence in order to be able to trust and invest in life again. Research by Keesee et al. (2010) and Lichtenthal et al. (2010) into bereaved parents' construction of meaning concentrates on whether parents managed to make sense of the death of their child, and if they derived any benefit from the experience (Keesee et al. 2008; Lichtenthal et al. 2010). Wheeler (2001) looks at this search for meaning from the angles of a 'search for cognitive mastery' on the one hand and a 'search for renewed purpose' on the other. To Janoff-Bulman the two primary connotations of meaning in the context of trauma are meaning as *comprehensibility* (making sense) and meaning as *significance* (finding value or worth) (Janoff-Bulman & Frantz 1997).

In this paper, we focus on the role of spirituality in the process of coping with the loss of a child. Parents' narratives portray various elements of spirituality. These can include rituals that are important at the time of the child's death or in the aftermath to it, the search for meaning and coherence, and specific spiritual experiences of bereaved parents like 'after-death communication' with the child or connectedness to transcendence (Klass 1999; Talbot 2002; Meert, Thurston et al. 2005).

Many definitions of spirituality include both *active* searching for and *receptive* finding of meaning. 'Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred' (Puchalski, Ferrell et al. 2009). This relates directly to the search for coherence, the person's worldview or faith, and the encounter with transcendence (Klass 1999). Spirituality is concerned with both 'the sacred' (God, gods, transcendent powers, etc.) and the search for meaning, and helps individuals to come to terms with ultimate issues (Pargament 1997).

Although spirituality seems to be generally accepted as an important domain of bereaved parents' grieving process (Barrera, O'Connor et al. 2009), visual or auditory after-death experiences of the dead child are often viewed

sceptically. They are categorized as 'hallucinations' and described as 'transient illusory experiences, often occurring within a few weeks following the loss'. Hallucinations and illusions are considered to be expressive of 'searching attempts to find the deceased' (Worden 2009). Although these experiences are undeniably part of normal grief reactions, it is feared that if they occur too long after the initial grief phase they could indicate parents' inability to detach themselves from their child and reorganize life in the altered circumstances (Field 2008).

In our research we describe such spiritual experiences encountered in the narratives of grieving parents. We want to assess their role in attributing meaning to the loss of the child, in finding comprehensibility and/or significance, and in coping with the continuity and discontinuity of their narratives. The main question, then, is: what role do spiritual experiences play in the narrative construction of continuity and discontinuity in the changed relationship between parents and the deceased child? We opted for a narrative approach because we are interested in people's subjective constructions of their experiences (Ganzevoort 2011). The narrative approach permits various reconstructions of meaning in life stories. It is especially useful for our purpose because of the complexity of observing continuing bonds with the deceased and because of the many nuances of finding and expressing meaning.

After explaining our method we first describe the spiritual experiences we encountered in the stories parents told us. We then explore their narratives from the perspective of continuity and discontinuity and of finding comprehensibility and significance. In conclusion we explain our position in the field of researching the importance of finding meaning after bereavement.

Method

Participants

This paper uses the results of a pilot study for a larger research project in which we will investigate wellbeing and narrative construction of meaning among bereaved parents at a pediatric intensive care unit. The project will include both retrospective and prospective accounts and measures. In this pilot study we included a sample of eight mothers and one father of children who died of cancer. The women participated in a project focusing on support for parents in the palliative phase of their child's illness. Seven of these mothers and the father (partner of one of the mothers) were interviewed in their homes. All were native Dutch. All had a college or university education and all but one were employed at the time of the interview. They were all active in society, having jobs, and all said they were enjoying life again – an indicator of successful coping.

Six of the women were still married to the father of their child. At the time of death the children ranged in age from two to seventeen. Illness duration

ranged from two months to fourteen years, and the time lapse since their death ranged from eighteen months to almost twenty years. The parents came from different religious backgrounds. Four mothers and the father were raised in Roman Catholic families, although none of them were practising Catholics at the time of the interview. One mother was an active member of a Protestant church community. Two were explicit nonbelievers. One mother had been involved with spirituality since her youth and participated in an esoteric community. For greater variety we included three Muslim mothers (two Turkish and one Moroccan) whose children had died of various illnesses in the Rotterdam Children's Hospital. Their ages at the time of death were four months, eight months and nine years. These interviews were conducted by a Muslim hospital chaplain.

Data collection

Individual semi-structured qualitative interviews were conducted in the homes of the participants. The interview was explained as focusing on possible special, meaningful experiences at the end of the child's life. A typical first question was: what was your life like before your child's illness? All participants started with a detailed description of the illness itself, leading up to the death of the child. The stories usually consisted of three phases, starting with the period leading up to the moment of death. In most cases this occupied about three quarters of the total time of the interview. Next they focused on the period from the actual death up to the funeral. They ended with the phase since the death. In this latter part of the narrative they focused mostly on what was meaningful to them and on whether they felt their child was still close by. The interviewer intervened as little as possible. Towards the end of the interview some questions were asked about experiences others had mentioned, with the aim of comparison.

The interviews lasted from one to three hours. They were audio-recorded and transcribed verbatim. In some cases the participants contacted the researcher afterwards because they had realized there were themes they wanted to add. The material was analysed using a Grounded Theory approach and open coding. Related codes were combined and categorized through repeated comparison of similarities and relationships. The final identification of core categories led to a clearer understanding of the contents and structures of the narratives and to an answer to the research question. At this stage we did not use further procedures like selective coding.

Spiritual experiences

We start our explorations with a description of the spiritual experiences of the parents and their children. These are portrayed as receptive rather than active sources of meaning. Several categories of experiences emerge from the narratives.

Premonitions

All mothers mentioned what one of them called 'a deep knowledge from within'. They all had premonitions of what was going to happen, whether it was the (fatality of the) illness or the imminence of death. Three of them indicated that they had always felt special concern for this specific child. One of them said that since childhood she had thought she should have two children, 'because one of them was going to die'. Four of the non-Muslim parents, all Muslim mothers, and – according to the narratives – two of the children had had vivid, 'realistic' dreams or visions relating to the child's impending death. For one Muslim mother the main criterion to decide if the dream was true was the special feeling she had with every predictive dream. Some of these dreams were very concrete ('I dreamed of a Chinese blind girl. Next day we heard our son was probably going to be blind'. 'A week before her death I heard a male voice in my ear saying: Thursday. And on Thursday she died') These mothers did not speak to others about the dreams at the time for fear 'that they might come true', or because they feared they would be misunderstood. All participants said they were convinced that their child knew he or she was going to die. One of the children wrote a little poem: 'little god, little god, am I going to die?' Another boy very calmly declared he was going to die, even though he had never wanted to talk about death before that.

Three of the parents had explicitly talked with the child about what heaven or the transition to heaven was like. One of the children never wanted to talk about what could happen to him, but at some point shortly before his death had given away his 'legacy' (toys) and had gone through the story of his life with the help of photographs. He was reconciled with his sister before it was too late. In the final moments not one of the children was afraid. One of them said: 'I want to say goodbye to life. I want to go to heaven'. Four of the children expressed their faith in God and Jesus to the amazement of their parents, and five of them said explicitly they were going to heaven.

The moment of death

The moment of death was extraordinarily intense: 'how can I explain what it is like when you see life leave your child...' Yet it also was described as a moment of total connectedness to life, to God, and to the child. Three of the mothers did not speak in those terms, as the moment was traumatic and sudden.

For six of the parents the moment of death was very special yet ambiguous. The father described the final days as 'living in a cocoon', where he experienced the essence of life itself. His son saw 'helpers' to facilitate the transition 'to the other side'. In the midst of their anguish three parents experienced a special peace descending upon themselves or their child, or felt 'God had never been so near'. Four of the participants said they 'saw' the soul of their child leaving the body and two of the children had smiles on their faces when they died. Two of the stories mention a voice in the mother's or a sister's head immediately after the child's demise saying 'I am okay; I am with you'.

Postmortem presence

In the postmortem period all parents experienced the presence of their child. Seven had a sensory experience: they felt a hand on their shoulder, smelled, saw or heard the child. Both partners separately saw an appearance of their son some months afterwards. Six parents saw an animal that had a special link with their child at meaningful moments and took it as a sign from their child; it involved a bird (twice), a cat, a mountain goat, a butterfly and a dragonfly.

Six of the parents narrate occasional or frequent signals or signs from their children, not only in the beginning but right up to the time of the interview. They tell of things moving inexplicably, of electrical appliances like lights or radios operating mysteriously without human intervention, and how special songs would come to them at meaningful moments. The parents related these signs to the deceased child in some way. It was always connected with the thought that there was something more between heaven and earth, even though one of them did not believe heaven (or God) existed. She 'hoped for it', though.

For the Islamic mothers dreams were the cardinal way of experiencing contact with God or their child. They all experienced continuing contact with the child in their dreams. 'I see her then in my arms', 'I see him walking, playing, with no scars'. One of them also conversed with her dead brother in her dreams. Note that the Muslim mothers received 'signs' only in their dreams. In Islamic culture dreams are an accepted way in which Allah conveys messages (Edgar 2011). Although a dream can also come from Satan, it was clear to the mothers that theirs came from God.

Not coincidental

Bereaved parents seem sensitive to 'coincidencing', attributing meaning to what other people are inclined to call coincidences (Nadeau 2008). 'Coincidence doesn't exist' was a common remark. For most of them they signified a special connection with something beyond themselves. This also seems to be the implication of the dreams and vivid visions both some of them and their children experienced and by the premonitions that feature prominently in the narratives, in one case even going back to childhood.

Nine of the parents said that during the whole process many things happened that were 'not coincidental'. Various experiences were classified under this theme: the fact that the children had been able to do something important just in time ('a day later it would have been impossible'), people arriving at exactly the right moment, meaningful words, texts offered at exactly the right time, meaningful dates. One mother had had a life-long fascination with the number three; her son died on 3 December 2001 at 11h10.

Continuity and discontinuity

A central theme in the narratives is the dialectic relation between continuity and discontinuity. The loss of a child has an enormous emotional impact on parents. A dominant psychological theory is that one should not walk away

from the immense pain that the loss evokes. In fact, the core of mourning is working through that grief. It appears to be essential for the bereaved person to realize that the deceased has gone (Worden 2009). The psychoanalytic tradition that (under the influence of Freud) propounded the necessity of relinquishing ties with a deceased person has had an immense influence on the scientific literature on mourning and grief. This long-standing belief is challenged by empirical evidence that continuing bonds with the deceased are not a manifestation of a maladaptive mourning process (Klass 1996). Discussion in the field now centres on the way in which the continuing connection with a deceased person is either effective or ineffective in coping with bereavement (Stroebe 2010). To see a dead person walk into the room can be a normal neurological reaction in the first phase of mourning, but continuing awareness of the deceased person's presence and closeness, even in sensory reality, can be a sign of maladaptive responses (Field 2008).

Continuing bonds

Our participants' narratives portray a differentiated function of ongoing bonds. Most parents experience a lasting relationship with their deceased child, but they are fully aware of the discontinuity and finality of their loss. The fact that they all spoke at length of the extremely difficult time of the child's illness leading up to death suggests that they certainly don't walk away from this reality. The greater part of the parents' narratives was devoted to the illness, from the first symptoms and the diagnosis to the moment of death. They all felt a need to tell the story in great detail. The feeling that their child still played a part in their lives and showed himself or herself in occasional signs did not take away their pain. Their child's physical closeness was painfully missed even when they described sensory experiences of its presence.

One mother described her inner life as a two-track reality. She had resumed full participation in her family life and social context, but at the same time it was like 'having a hole inside'. The period of their child's illness and death had damaged relationships in the social context, had bruised personalities and made parents extremely vulnerable, as one mother described it. Others talked of negative meanings emerging in their lives, using metaphors like 'the world was a devastated landscape', 'I know how it feels to be in hell, to burn continually without dying'. For every parent the death was a harsh, inevitable reality, leaving no doubt as to the end of the child's life. What remained was an enormous void in their lives. At the same time they had experienced resilience and strength. The mother talking about hell also mentioned happiness and gratitude for what she had learnt in the process.

Discontinuity in place

Discontinuity and continuity alternate in the relationship with their child. This is expressed, for instance, in terms of location. They were painfully aware that their child was 'not here'. Yet the narratives show they all thought their child was 'somewhere', not 'nowhere'. What they called this somewhere depended on their beliefs or worldview. For some, using Christian terminology, it was

'heaven'. Two others called it 'the spiritual world'. Three mothers and the father did not specify the place, neither did the mother who did not believe in heaven but said, 'I wish I knew where he is'. The Muslim mothers spoke of 'paradise' and 'being with Allah'. It seemed helpful for parents that their children referred to the place they were going to as 'heaven', even though three of them were surprised by the spirituality of their child, because they did not practise any religion in their family.

Tellingly, only two mothers spoke of the moment of death in terms of dying. The others all used the metaphor of 'going': 'you may go', 'at that moment he went', 'it seemed at times that he had gone and returned'. Some said their child 'crossed over'. The father had told his son at a certain point that dying was comparable to the Harry Potter story: to take the train to Hogwarts one had to run through a wall in the railway station, the entrance becoming visible only once you are right there.

The mother to whom the Christian faith was focal had said to her daughter prior to her death that she should not come down again but should 'stay with Jesus'. Once when she felt that her daughter wanted to 'come', she prohibited it again. In some of her dreams she had the feeling that she herself 'had gone up' for a moment. The Muslim mothers also believed that their child did not 'come down' but was with God. "It gives me peace of mind... that a (dead) person is not gone. The body may be gone, but the spirit is still over there. Not with me, but there. The person is still over there, that is what gives me strength." For nine of the mothers it had become evident in the process that the soul of the child had left the body. One mother said: "When she passed away that whole body relaxed, that is logical, but it was so special to see it happen. I knew immediately: she is out of it, she is gone." Another mother said: "I am convinced she went in peace. That she saw something. Because when she went, she said: I am dying now... and after that it was immediately over. I am convinced there is somewhere where we will meet again." Comparable to the underlying assumption that the child is not 'nowhere', 'gone forever' is also not part of the parents' vocabulary. The thought that there is a reunion after death features in the majority of the narratives (Benore 2004).

Continuity in communication

Although discontinuity in place (and time) plays a key role in understanding the reality of death in the stories, in many cases there is continuity in communication. As described above, there are many experiences of presence and signs. Yet the experience that their child communicated with them after death was not always part of a coherent meaning system. Their child was gone, in heaven or somewhere like that. In some cases memories were even fading. Nevertheless, at times they felt their child was still near them, especially when they were going through difficulties or were away from home. In these stories the child seems to be both transcendent and immanent (cf. Klass 1999, 107). The mother whose daughter died twenty years ago did not experience many signs, but she visited a spiritual medium, who said she had

received a message from the deceased daughter that the mother had done well in helping and caring for her daughter. This was very important to the mother.

For these parents continuity and discontinuity in the narrative are ambiguous. Good, meaningful moments are linked with bad ones. They are two sides of the same reality. They cannot speak of meaningful experiences separately from the immensely painful story that needs to be told. The meaningful moments, including 'after-death communication', could only come into their own within the narrative of pain, anxiety and despair. They belonged together. Two mothers, for example, called the period of treatment of the cancer a terrible but at the same time positive and special time. The moment of death was in some cases terrible and yet totally transcendent.

This dialectics of continuity and discontinuity that is central in many of the stories can be seen as the major challenge for parents after the death of their child. The construction of a meaningful narrative requires both acknowledgment of the reality of death and preservation of the bond with the child. The existential/spiritual experiences described here seem to meet these complementary, contradictory requirements.

Comprehensibility and significance

The experience of transcendent reality in some way was common to all parents, although not always expressed in religious or spiritual language. Only the Christian and Muslim mothers (and one of the others) referred to God. But the interaction with their dead children seemed to merge into their other experiences of transcendent reality (Klass 1999). The question is if these spiritual experiences further both the search for comprehensibility and the search for significance.

Significance of 'the special child'

First and foremost the narratives stress the meaning of the child itself. Six of the parents described their child's personality as very special, always happy in all circumstances, gifted, extremely sociable, and able to communicate with all children and many adults. They all said the child changed in the course of the illness, appearing to be mature (even the two-year-old) or, as one parent put it, 'an old soul'.

According to the parents' stories their children's lives had been meaningful. They had meant a lot to many people, either because of their personalities or because of the process they had gone through. They had not lived 'for nothing'. One of the Muslim mothers, for example, told what she had learnt from her son: patience, acceptance and gratitude. All parents had lost their fear of death as a result of the process. All but one thought they would in some way be reunited with their child at the hour of their own death. This focus on the unique meaning of the child featured prominently in the narratives.

Spiritual development

The spiritual experiences had different effects on the beliefs or worldviews of the bereaved parents. Five parents retained their old worldviews and beliefs (Christian, Muslim, and spiritual) and were able to interpret their children's deaths in that light, even though it entailed some struggle and adaptation. One of them stuck to a nonbelieving worldview, but still longed for answers. Five parents looked for new worldviews that fitted their experience. For two of them this was a crucial element of the grieving process. The others only seemed interested in finding a worldview that accorded with their feeling of connectedness to their child.

If we examine the stories in more detail, it is clear that their searches relate to the traditions in which they live. One mother continued to believe that there is no life after death but also expressed ambivalent views. On the one hand she called herself rational for not believing in God or heaven, on the other she said she thought there was something more between heaven and earth. She did not think she was going to be reunited with her child, but hoped she was wrong.

Two mothers were not spiritually engaged before the illness and death of their child but became so afterwards. The first mother met an 'energetic therapist' that guided her son through his illness, hoping to diminish his suffering and fears. The therapist touched the son at a spiritual level without ever seeing him in person. Afterwards the therapist explained to the mother that her son's illness was the result of a struggle in a previous life that had involved many people, and that his purpose in this life had been to restore the spiritual equilibrium. This gave the mother a clear, coherent interpretation of her son's suffering. It also gave her a strong purpose in life, because her soul had been entrusted with the task of guiding him through the process.

The other mother said: "Before my son's death, I was never occupied with spirituality. But it came to me quadraphonically [from all sides, RRG&NF]. We experienced so much that cannot be explained. These things cannot be coincidental. Yet I have no explanation for these happenings." She started to read many spiritual books and was especially interested in the Tibetan Book of the Dead. Yet she failed to find a wholly satisfying explanation for the death of her son; it remained unacceptable.

A third mother, who had been spiritually engaged since childhood, related how her spirituality had not changed but only intensified. She had a clear picture of what happened after death. 'Anyone who dies has only gone away from here. We come to earth to learn something ourselves, or to teach others. You don't go before your time.' This view offered her solace, which was especially important because of the medical errors surrounding her son's death.

The mother who had been an active member of a Protestant church recounts many conflicts with her God. She felt great anger towards him, asking 'What are we being punished for?' At the same time she felt she was receiving divine support. She describes three turning points in which her anger and despair

were taken away. Since she could not relate the love of God to her daughter's pain, she undertook a spiritual search for some kind of explanation. In this search she set the condition that the outcome should not conflict with the belief that 'Jesus Christ is my Saviour'. After reading and hearing many different opinions she concluded that it might be that a soul comes to earth from God with the assignment to learn certain things, after which it can return home.

For the Islamic mothers their faith in God intensified, although two of them had wrestled with God, asking if they were being punished for some reason. All three came to the conclusion they had been tested or tried and that their children are in a happy place where they are better off.

Search for meaning

Most of the parents said they had not been preoccupied with the meaning or sense of what was happening to them during the time of the illness. At that time they just tried to survive. Questions about the sense of suffering at that time were considered to 'undermine their strength'. The important thing was not the meaning *of* the situation but 'what was meaningful *in* this situation', what helped them, what gave them strength.

After the child's death the search for meaning became important in varying degrees. Seven of the parents searched for some kind of explanation, like the notion that their child's spirit had come here for a reason and, after fulfilling that task, was allowed to go back 'home'. This did not take away their grief but it gave them some solace. For six mothers and the father it was important to stress that *at the same time* there was no explanation that would justify the death of their children. Their death was wrong, unjust, unacceptable. No explanation, religious or otherwise, could take that away. Even though there was no satisfactory explanation that would make them accept the necessity of their child's death, they expressed the view that certain things in the narrative – while beyond human comprehension – were 'meant to be', not coincidental, (Klass 1999).

Discussion and conclusion

The narratives of grieving parents confirm that finding meaning in bereavement is definitely important to parents who lose a child. The narrative approach gives them the opportunity to express in their own words what finding meaning entails. This obviously raises methodological questions regarding the status of these narratives: to what degree are they co-constructed by the research situation? And how are retrospection and reflexivity accounted for? Our narrative approach is not meant to be an objective observation of stories that already exist 'out there', but to witness to the stories constructed by participants and shared with the researcher. This means that specific stories emerge and are presented in a specific way, but it does not detract from the status of the material. On the contrary: if we believe

that meaning is always constructed and reconstructed in narratives, contextualized in specific social settings, and combine reflection, retrospection and performative intentions, then the stories told to the researcher merit analysis just as much as any other story. Participants try to find and present meaning in stories about their experiences when telling them to a specific audience (Ganzevoort 2011).

The endeavour to 'make sense' of the loss definitely plays a role in these narratives. Seven (of the eleven) parents tried to find a satisfactory explanation that would make them accept the death, using a religious or spiritual framework. Yet the intensity of the pursuit of meaning varied greatly and the attempt to make sense did not always lead to a coherent worldview. Others stressed that they did not understand at all how life and death interrelate, and three parents went so far as to say they did not want to find coherence in the process as it seemed to diminish the unacceptability of their child's death. Yet this denial of the comprehensibility of the loss did not indicate that they found no meaning at all in the loss, nor did it seem to intensify their grief.

To all of them it was essential to find significance in the process. Above all the child's actual life had immense worth and value. An essential part of the narrative of the grieving process was the conviction that the children's lives, though dominated by suffering, were meaningful. They meant a lot to others, they enjoyed life, they lived it to the full. The meaning of their lives extended beyond their families.

The narratives suggest that making sense of *the child's life* was more important than making sense of *their death*. The fact that a child dies young is a narrative anomaly that can be compensated for to some extent by the thought that their lives were not 'normal, ordinary'. Research that concentrates primarily on parents' ability to make sense of their loss, even if it makes use of open-ended questions (Keesee et al. 2008, Lichtenthal et al. 2010), may miss the nuances and contradictions that are part of the personal construction of meaning emerging from the narratives of grieving parents .

The relationship with the child also had lasting significance in the parents' lives. Although they carried the pain of the loss within them, in some way they still felt connected with the child. The bond continued. Spiritual experiences bridged the gap between the child that had passed away and their own reality. Although several parents had little or no affinity with either religion or spirituality, the concept of transcendence featured in their narratives in some way, for instance in statements like 'everything has a reason' and 'coincidence doesn't exist'. This does not imply that they all believed in a predetermined plan. It means that, implicitly or explicitly, they felt in contact with a transcendent reality that somehow integrates the incoherent experiences of life and death. The way they experience this transcendence may be imbedded in a specific cultural or religious tradition. The Muslim mothers, for example, experienced this transcendence especially in dreams

and did not narrate symbolic events or sensory experiences. In dreams, however, contact with their child was possible.

The narratives show that part of parents' *construction* of meaning builds on the experience of having *received* meaning, either from their child or from a transcendent world. For all these grieving parents special moments of connectedness felt like an indication that their child was not completely gone and was still part of their lives. They linked this with experiences in the period prior to the child's death. These experiences became meaningful in retrospect: dreams, things their child had said or done, and many things that did not seem coincidental. They ascribed these experiences to the same transcendent reality they thought their child was now part of.

The narrative approach suggests that it is *significance* and not *cognitive mastery* (Wheeler 2001) or *making sense* (Keese et al, 2008, Lichtenthal et al. 2010, Neimeyer et al. 2006) that predominates in the search for meaning, though the latter certainly features in the stories. The narratives show the ambiguity of the mourning process. The loss doesn't make either sense or no sense: it does both. In the same way parents experience both continuity and discontinuity in the bond with their child. Our material illustrates that spirituality plays a major role in the search for meaning. The fact that parents still feel in contact with their child, including visual or auditory signs long after the initial period of mourning, does not indicate maladaptation to the loss (Field 2008). All the parents had adjusted successfully to their situation, recognizing fully that their child was dead.

To understand the dialectic relationship between continuity and discontinuity in the life stories of grieving parents, spiritual experiences as such need to be taken seriously as part of the transformation of the ongoing bond between parents and the child that passed away (Benore 2004).

Although the narrative is a personal construction, all the parents found certain things, actions, memories, and experiences meaningful. In their stories they seemed able to reconstruct the fundamental assumptions of a meaningful and benevolent world and the worthiness of the person (both the child and the parent). All this is reconstructed as being in a different way and on a different level than before, incorporating the pain, grief and senselessness of the loss. The mourning process consists of many layers of addressing meaning. Contradictions and ambiguities are among these.

Spiritual experiences are part of the ongoing narratives of parents who lost their child. Their main function is to embody and imbed the continuing bond with their child and with transcendence. In this way they further the continuation of their life story.

References

- Barrera, M., K. O'Connor, D'Agostino, N. M., Spencer, L., Nicholas, D., Jovcevska, V., Tallet, S., Schneiderman, G. (2009). "Early parental adjustment and bereavement after childhood cancer death." *Death Studies* **33**(6): 497-520.
- Benore, E. R. & Park, C.L. (2004). "Death-specific religious beliefs and bereavement: belief in an afterlife and continued attachment." *The International Journal for the Psychology of Religion* **14**(1): p.1-22.
- Calhoun, L. G. & Tedeschi, R.G. (eds) (2006). *Handbook of posttraumatic growth: research and practice*. New York, Erlbaum.
- Dijkstra, I. (2000). *Living with loss. Parental grieving for the death of their child*. Utrecht: Thesis. Department of Clinical Psychology, Utrecht University
- Edgar, I. (2011). *The dream in Islam: from Qur'anic tradition to Jihadist inspiration*. Oxford, Berghahn.
- Field, N. (2008). Whether to relinquish or maintain a bond with the deceased. M. H. Stroebe, R.O. Schut, H & Stroebe, W. *Handbook of bereavement research and practice: advances in theory and intervention*. Washington, American Psychological Association Press: pp. 113-132.
- Ganzevoort, R. R. (2011). "Narrative approaches." Miller-McLemore. *The Wiley-Blackwell Companion to Practical Theology*, Chichester, Wiley-Blackwell: 214-223.
- Hogan, N. S. & Schmidt L. A. (2002). "Testing the grief to personal growth model using structural equation modeling." *Death Studies* **26**(8): 615-634.
- Janoff-Bulman, R. (1992). *Shattered assumptions. Towards a new psychology of trauma*. New York, Free Press.
- Janoff-Bulman, R. & Frantz, C. M. (1997). "The impact of trauma on meaning: from meaningless world to meaningful life." M. Power & C. R. Brewin. *The transformation of meaning in psychological therapies*. Chichester, England, Wiley & Sons.
- Keesee, N. J., Currier, J. M., Neimeyer, R.A. (2008). "Predictors of grief following the death of one's child: the contribution of finding meaning." *Journal of Clinical Psychology* **64**(10): 1145-1163.
- Klass, D. (1999). *The spiritual lives of bereaved parents*. Philadelphia, Taylor & Francis.
- Klass, D., Silverman, P.R. & Nickman, S.L. (eds) (1996). *Continuing bonds: new understandings of grief*. Washington, DC, Taylor & Francis.
- Lichtenthal, W. G., Currier, J. M., Neimeyer, R.A., Keesee, N.J. (2010). "Sense and significance: a mixed methods examination of meaning making after the loss of one's child." *Journal of Clinical Psychology* **66**(7): 791-812.
- Meert, K. L., Thurston, C. S., Briller, S.H. (2005). "The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study." *Pediatric Critical Care Medicine* **6**(4): 420-427.

- Nadeau, J. W. (2008). *Meaning-making in bereaved families: assessment, intervention, and future research*. Washington, American Psychological Association Press
- Neimeyer, R.A., Baldwin, S.A. & Gillies, J. (2006). "Continuing bonds and reconstructing meaning: mitigating complications in bereavement." *Death Studies* **30**: 715-738.
- Nolen-Hoeksema, S., Larson, J. (1999). *Coping with loss*. Mahwah, New Jersey. Lawrence Erlbaum Associates.
- Pargament, K. I. (1997). *The psychology of religion and coping. Theory, research, practice*. New York, Guilford Press.
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K., Sulmasy, D. (2009). "Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference." *Journal of Palliative Medicine* **12**(10): 885-904.
- Rosenblatt, P. (2000). *Parent grief: Narratives of loss and relationship*. Philadelphia, Taylor & Francis.
- Stroebe, M., Schut, H. & Boerner, K. (2010). "Continuing bonds in adaptation to bereavement: toward theoretical integration." *Clinical Psychology Review* **30**(2): 259-268.
- Talbot, K. (2002). *What forever means after the death of a child. Transcending the trauma, living with the loss*. New York and London, Routledge.
- Tedeschi, R. G. & Calhoun, L.G (2004). *Helping bereaved parents; a clinical guide*. New York, Brunner-Routledge.
- Wheeler, I. (2001). "Parental bereavement: the crisis of meaning." *Death Studies* **25**: 51-66.
- Worden, J. W. (2009). *Grief counseling and grief therapy. A handbook for the mental health practitioner*. New York, Springer.